

# Family Partnership Newsletter



MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES

HEALTH.MO.GOV/FAMILYPARTNERSHIP

## What's in a Name?

by Shari Eberts, [Living with Hearing Loss](#)

### The language of disability is constantly evolving.

Historically, disability was discussed within a medical model. Doctors discussed people's inability to do something that a "normal" body could do — whether that was walk, hear, see or whatever. It was a "dis" ability, "dis" meaning apart or asunder in Latin. Sometimes derogatory words like "crippled" or "retarded" were used, perhaps from a lack of understanding. People with hearing loss may have been called "deaf and dumb," especially if they had trouble with speech. The term "hearing impaired" also reflects a medical model mentality.

The medical model transitioned into person first language, as in "a person with a disability" or "a person with hearing loss," stressing that the person comes first and the disability second. This is the type of language I typically use when I talk or write about myself. This wording is often used in public documents, on websites, and by hearing loss organizations because it is respectful, but it can be wordy and cumbersome to use.

Recently, identity first language has become popular, for example, "I am disabled." This assumes that the person part is a given and implies membership in a community of others with that same disability. Many of the panelists at the workshop felt empowered when using this type of language.

For hearing loss, identity first language is complicated by the Deaf community, which has defined Deafness

culturally to include using sign language to communicate. For "deaf" people who don't sign or who aren't culturally deaf, the word doesn't seem to fit, leaving us without a one word descriptor that accurately reflects our state of being.

Evolution in language makes it challenging to know what to say sometimes. One audience member commented, "It used to be okay to say visually handicapped, then visually impaired, then partially sighted. I don't know what is right anymore." Language

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## 2022 Family Partnership Parent and Caregiver Retreat Announcement

On behalf of Family Partnership, we would like to inform you that due to the continuation of the COVID-19 pandemic, we are unable to host our annual Parent and Caregiver Retreat in 2022.

While we will miss seeing you all in person, we feel this is the safest option for all involved at this time. We look forward to hosting an even better experience for all our families in 2023.

If you need any assistance, please contact your Family Partner. We hope you stay safe and thank you for your continued understanding! Please watch for upcoming announcements for virtual activities hosted by the Family Partnership.

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often reflects society and culture, meaning change is likely the only constant.

### What you call yourself may change as your feelings shift.

Many panelists noted how their own use of language changed over time as they become more accepting of their disability. Often their path took them through the medical model, to person first and finally into identity first, as they discovered a community of others like them. Seeing all the wonderful things that people with similar challenges to you have accomplished can be inspiring and jumpstart confidence in your own abilities.

This is definitely true for me. Before I came out of my hearing loss closet, I referred to hearing loss only when absolutely necessary, saying something like “I don’t hear well.” Now I typically say “I have a hearing loss,” or “I wear hearing aids.” Occasionally, if I want to have more impact, will say “I’m a little bit deaf.” That really gets people’s attention, perhaps because deafness is seen as more serious. Because of the cultural associations of using the word deaf (Deaf), I find it difficult to use the term regularly — primarily because I don’t want to give a false impression that I use sign language.

There probably is no one size fits all solution for all disability groups and for all individuals within each group. Language is personal, and reflective of our own experiences and feelings about our disability.

### Having proper language to use reduces stigma and fear.

Without the proper vocabulary, people are often reticent to discuss disability because they feel uncomfortable or nervous about offending someone. This makes disability a stigmatized unmentionable. When people know the right words to use, it makes it easier to have a conversation about disability. This makes it simpler to create work-arounds when needed and to provide a more inclusive environment.

Sometimes tone is more important than the words that are used. Many panelists felt that being treated with respect was the most important thing, regardless of what language people used. All wanted to avoid being deified as well. One panelist commented, “I am not a saint or a super human, I am just living my life. But don’t ignore my disability either. That is just not reality.”



## Hearing Aids Are NOT Like Glasses

by Shari Eberts, [Living with Hearing Loss](#)

*Are hearing aids like glasses?  
Will your child be able to hear “perfectly”?*

### 10 reasons why hearing aids are not like glasses!

1. They do not restore your hearing to “normal” — things will be louder, but not always clearer, making it difficult to understand speech.
2. They amplify all sounds, including those you don’t want to hear like the hum of the refrigerator and other background noise.
3. They are not seen as fashion accessories, although some hearing aids now come in colors.
4. They often remain shrouded in stigma and shame, unlike glasses which make you look “smart.”
5. They are not regularly covered by insurance making them prohibitively expensive for many.
6. They need batteries to function.
7. They can increase sensitivity to loud sounds.
8. They squeal at inopportune times.
9. They cannot get wet.
10. They are easily misplaced and can sometimes be mistaken for a snack by the dog given their size.

# Family Spotlight

## Meet the Shuster Family

Meet the Shuster family: Mike, Angie, Kaylyn and Allie. Mike is retired from 20 years in law enforcement and is now employed full time in the security technology industry. Angie is a former kindergarten teacher who currently works part time from home. Their life revolves around their two awesome girls, Kaylyn and Allie.

Mike and Angie were introduced to the special needs world when Kaylyn was born 18 years ago. From the day she arrived in the world at 11 weeks premature, she has had multiple medical needs. Kaylyn has cerebral palsy, hydrocephalus, epilepsy, scoliosis, colitis, Beckwith Wiedemann Syndrome, osteoporosis, dysautonomia, hyperoxaluria and chronic lung disease. For six years she used a trach. Kaylyn frequently relies on an oxygen tank to help her breathe. She uses a wheelchair and has a feeding tube. None of this stops her from living her best life, doing the things she loves. Kaylyn attends public school full time, loves church, music therapy, walks, watching Rachael Ray cooking videos, Special Olympics and Miracle League. She also enjoys long drives and lots of attention!!

Allie is their completely healthy, spunky and full of life 13 year-old. She started junior high this year and is on the cheerleading squad and is very involved with her church youth group. The Shuster family stays very busy running their girls back and forth to their many activities. They strive to balance everyday life with the medical needs that have to be addressed, and do everything they can to make sure their girls get the most out of life.

If you would like to share your family story and how you live your best life, please reach out to us at [FamilyPartnership@health.mo.gov](mailto:FamilyPartnership@health.mo.gov).



*Kaylyn enjoys music therapy, attending church and watching Rachael Ray cooking videos. Her medical conditions do not slow her down as she loves to be on the go. Her parents, Mike and Angie enjoy taking her on walks and long drives in the outdoors. Kaylyn's sister, Allie, enjoys cheerleading and is involved in her church youth group.*



### Share your family story!

Email: [FamilyPartnership@health.mo.gov](mailto:FamilyPartnership@health.mo.gov)



## Medical Home Resources

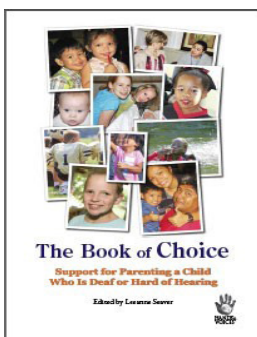
- Learn more about Missouri Medical Home:  
<https://health.mo.gov/living/families/shcn/familypartnership/pdf/MedicalHomeBrochure.pdf>
- Are you looking for a care notebook to organize your medical home? Check out the following resources:  
<https://www.ppcc-pa.org/toolkits-2/care-plan-book> and <https://www.kangarookidsclt.org/pouch>

## Resources:

- Free Tax Help: <https://irs.treasury.gov/freetaxprep>
- Broadband Connectivity: <https://www.fcc.gov/acp>
- Regional/County and Statewide Resources: <https://health.mo.gov/seniors/resources>
- The Connect with Me cards are a great tool to strengthen the connections and help start meaningful conversations between youth and adults. <https://health.mo.gov/living/families/connectwithme/>
- Love nature but can't make it outside? Subscribe to a free nature magazine. <https://mdc.mo.gov/magazines>
- Looking to go to an accessible playground? Find one near you and when you travel.  
<https://www.accessibleplayground.net/playground-directory/>
- Looking for a summer camp? <https://www.kidscamps.com/camps/missouri-specialneeds-camps.camp>
- Federal at-home COVID testing kit program: <https://www.covidtests.gov/>
- D/HH Resources: Birds singing, flowers blooming, pollen falling, eyes itching! Welcome Spring! Did you know that you should clean your hearing aids? The following article gives helpful tips for Spring Cleaning your hearing aids! <https://www.hearinglikeme.com/spring-weather-allergies-and-hearing-aid-maintenance>
- Advocacy App: Do you attend IEP meetings or 504 meetings? ASDC, NAD, Gallaudet, and Hands & Voices created an app that will guide you through important school meetings so you can effectively advocate for the opportunities your child deserves. <https://deafchildren.org/2019/07/new-parent-advocacy-app/>

## Free Book Resources

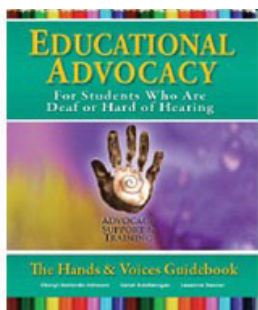
Below are FREE resources available through your Family Partner for Deaf and Hard of Hearing. Each family is limited to one book of each title. Limited books are available, so hurry to contact your Family Partner for Deaf and Hard of Hearing!



### ***The Book of Choice*** (Also available in Spanish)

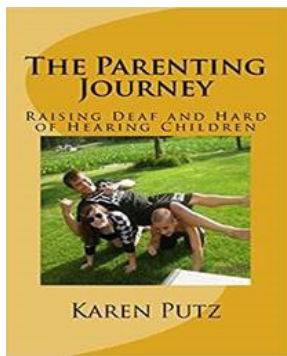
The Book of Choice is a wonderful expression of what we know to be true: parents sharing directly with other parents of children who are deaf or hard of hearing bring an essential kind of hope, inspiration and empowerment. This book is an amazing resource that captures that unique quality, and opens our minds to broader, more holistic views of parenting a child with hearing loss. It's just the kind of thing you'd expect from Hands & Voices.

- Christine Yoshinaga-Itano, PhD



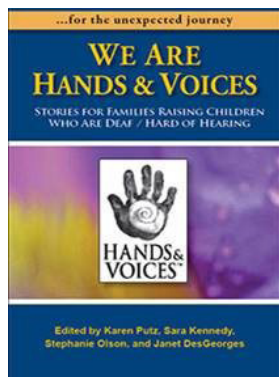
### ***Educational Advocacy For Students Who are Deaf or Hard of Hearing: The Hands & Voices Guidebook***

The H&V Guidebook is the essential book for families, advocates, and professionals who support the education of children who are deaf and hard of hearing. Can also serve as a textbook for students in the field.



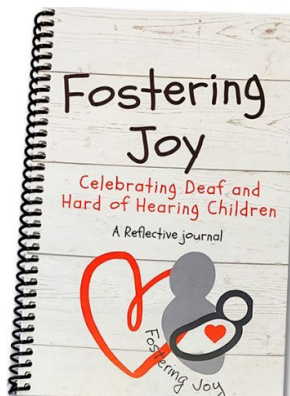
### ***The Parenting Journey – Raising Deaf and Hard of Hearing Children***

“Your baby is deaf/hard of hearing.” Those are the words that begin the Parenting Journey of raising deaf and hard of hearing children. Today, babies have their hearing levels tested shortly after birth. The Parenting Journey offers a unique look into the journey--one that is often filled with twists and turns. Karen Putz grew up hard of hearing and became deaf as a teen. When her own kids began losing their hearing, she figured she had all the answers as a professional and as a deaf person. She quickly learned it was a whole other ballgame to be a parent of deaf and hard of hearing kids. Karen shares the twists and turns of her journey and the wisdom she’s learned along the way. The Parenting Journey includes stories from a variety of parents who share their experiences.



### ***We Are Hands & Voices: Stories for Families Raising Children Who Are Deaf / Hard of Hearing***

At Hands & Voices our motto is simple: “What works for your child is what makes the choice right.” We recognize that the parenting journey is complex--and what works for one child may not be right for another. Whether you’re a new parent starting out or a seasoned parent looking back, you’ll find the ups and downs, the twists and turns, the challenges and joys in this collection of stories featuring many different perspectives. It is our hope that Hands & Voices, Stories for Families Raising Children who are Deaf/ Hard of Hearing will provide some guidance on your own journey.



### ***Fostering Joy: A Reflective Journal***

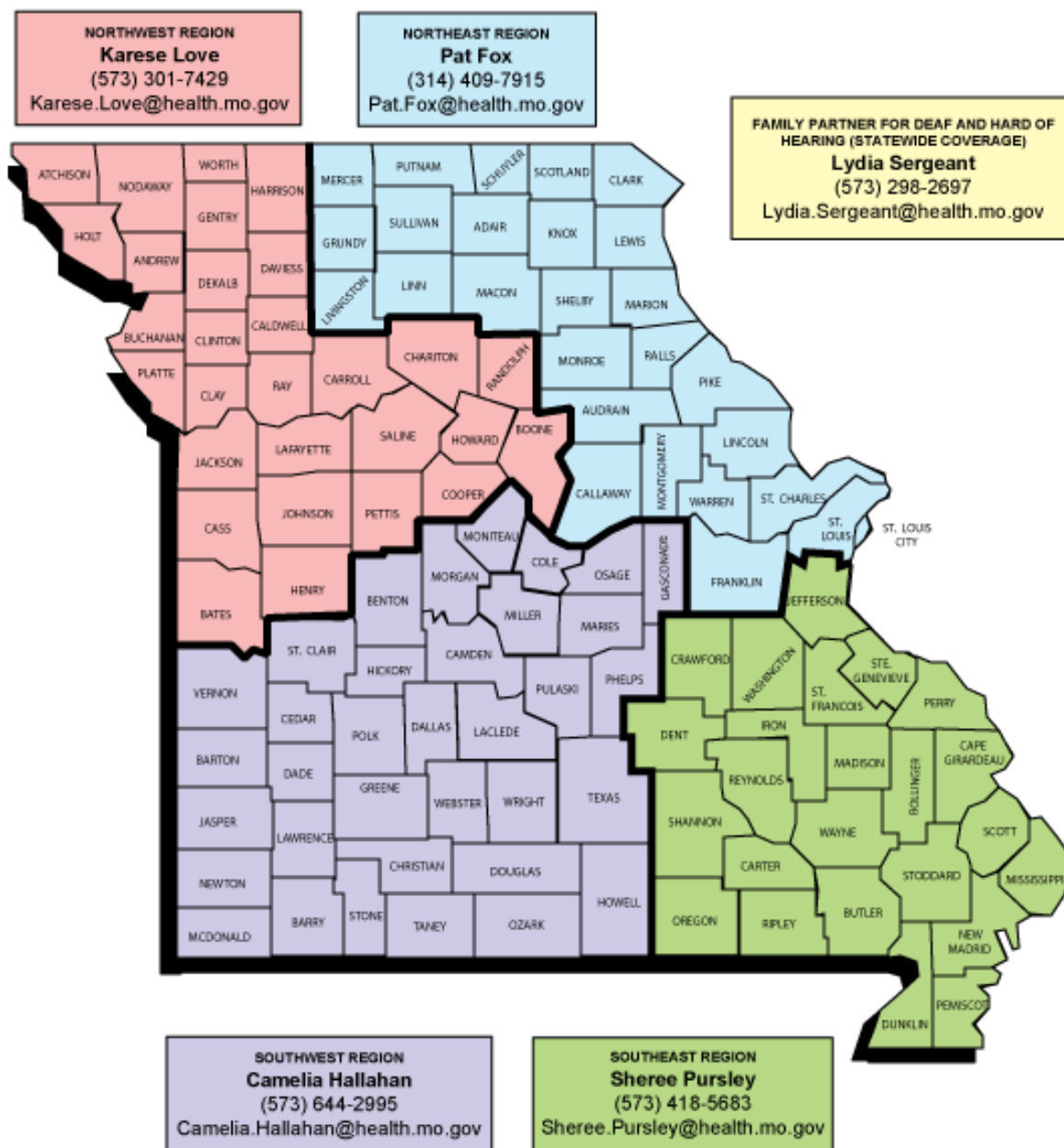
The Hands & Voices Fostering Joy Journal was created for parents/caregivers of children who are deaf and hard of hearing (DHH) to capture joyful moments on their parenting journey. By responding to a series of daily prompts, families are encouraged to establish an intentional practice of creating space for bonding experiences between caregiver and child, having an impact on the child’s social emotional development and well-being. The act of expressing gratitude through frequent journaling has been known to rewire the brain to be more positive and in this case, aid families in focusing on the strengths and gifts of their child. An additional feature of the journal are the whimsical drawings by a young artist who is DHH. The Fostering Joy Journal makes a wonderful gift to the family of a child who is DHH, especially those recently identified.



## **We Want to Hear From You!**

The Family Partners want to know what YOU would like included in future editions of the newsletter. Please take a few minutes to share your thoughts and complete the brief online [survey](#).

If you need help finding resources, your Family Partner is here for you!  
See the map to find your Family Partner or call our toll free number 800-451-0669.



Missouri  
**DHSS**  
Department of Health  
and Senior Services

Missouri Department of Health and Senior Services  
**Bureau of Special Health Care Needs**  
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**800-451-0669**  
**Health.Mo.Gov/FAMILYPARTNERSHIP**



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An EO/AA employer: Services provided on a nondiscriminatory basis.  
Individuals who are deaf, hard-of-hearing, or have a speech disability can dial 711 or 800-735-2966.